



Perinatal Mental Health Services

An analysis of people's experiences in Suffolk

Published March 2019

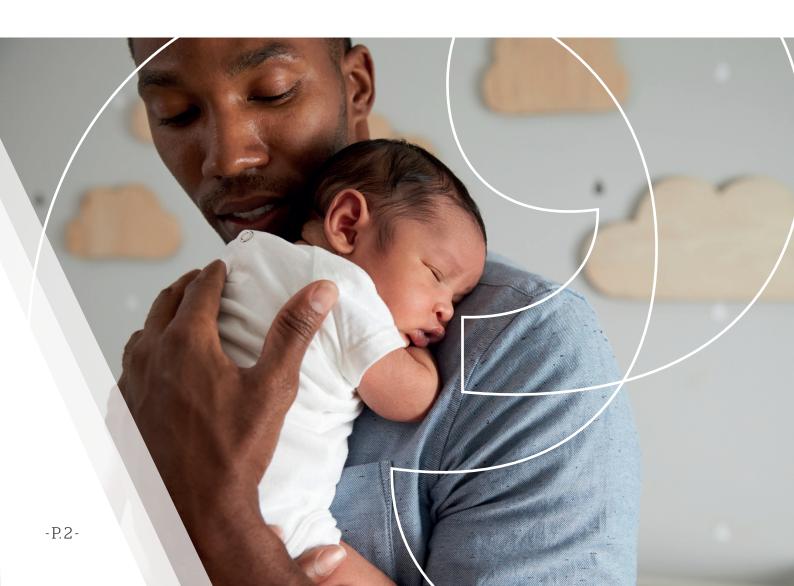
Introduction

Perinatal mental health problems are those which occur during pregnancy or in the first year following the birth of a child.

Perinatal mental illness affects up to 20% of women and are also common in men. Illnesses include a wide range of conditions such as anxiety and depression.

The Suffolk Perinatal Mental Health Service and Public Health Suffolk launched a survey in October 2018 to capture the experiences of both mothers and partners in Suffolk. Healthwatch Suffolk hosted the survey on their behalf. Data was collected between 25th October 2018 and 15th December 2018. Healthwatch Suffolk conducted an analysis of the responses and has produced this report to present the findings.

Please note that all participants indicated they were over the age of 22. This means that the views of younger mothers are not reflected in this report.



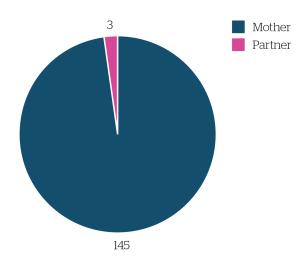
The results

152 responses were logged using a Survey Monkey link. After removing blank responses, a total of 148 responses were analysed.

About the participants

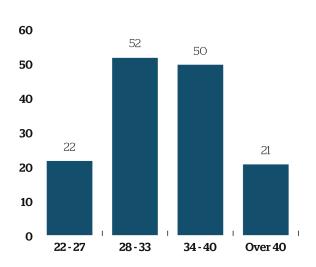
Mother or partner?

Most responses came from mothers. Three partners (all male) also completed the survey.



Respondent age

Mothers who responded were aged 22 or older.



Location

134 respondents provided a valid Suffolk postcode. A further 14 postcodes were outside of Suffolk. Please see Appendix A for responses mapped by location and level of deprivation.

Postcode	No.	Postcode	No.
CB9	15	IP23	1
IP14	15	NR33	1
IP4	11	IP8	1
IP28	7	IP27	1
IP30	7		
IP5	7		
CO10	6		
IP3	6		
CB8	5		
IP32	4		
IP31	4		
IP16	4		
IP17	4		
IP9	4		
IP2	3		
IP6	3		
IP13	3		
IP1	3		
IP11	3		
IP22	3		
IP12	2		
IP7	2		
NR32	2		
IP33	2		
IP24	2		
IP10	1		
IP29	1		

Did you have a mental illness before the pregnancy?

141 mothers responded to this question. 53% of mothers had a mental illness before their pregnancy, and 47% had not.

Two of the three male participants indicated they had experienced a mental illness before their partners pregnancy.

at-



53%

of mothers said they had experienced a mental health illness before their pregnancy

At what point did you start to notice something was not quite right?

32% noticed a problem before the birth. Over two-thirds of mothers (68%) noticed a problem after the birth, with 57% noticing within the first three months. The point at which mothers noticed a problem, varied between the types of illnesses they had.

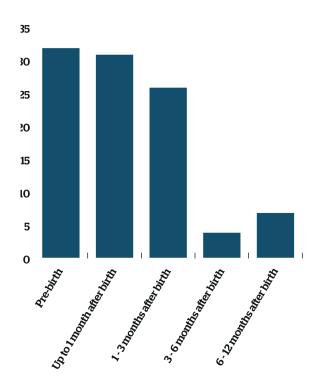
- A third of mothers with either depression or anxiety, picked up on the problem before their baby was born. A third picked up on the problem within the first month after birth
- Only 17% of mothers with PTSD noticed a problem within the first month after birth. The majority (42%) noticed between one and three months after birth.

Of the three male partners, two noticed a problem before the birth. The other noticed a problem 6-12 months after the birth.

Who first picked up on the change?

137 mothers responded to this question. Most (72%) said they picked up on the problem themselves. 20% said their partner, or a member of their family, picked up on it.

7% of mothers said the Health Visiting Team, their GP or Midwife picked up on it.



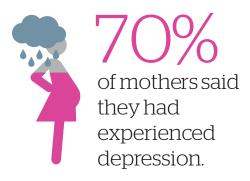




What mental health illness did you have?

136 mothers responded to this question. 70% said they had experienced depression (either by selecting 'Depression' or 'Postnatal Depression). Three male partners also responded to this question. All had experienced depression, and two had also experienced anxiety and panic attacks.

12% specifically selected 'Postnatal Depression'. 50% had more than one type of illness. Of this group, most had experienced a mixture of depression and anxiety. 67% had experienced "anxiety and panic attacks", 9% had experienced "PTSD", 4% had experienced "OCD" and 2% had experienced "psychosis".



Receiving help

The survey asked two questions about receiving help. One to determine who they had received support from, and another to determine which service.

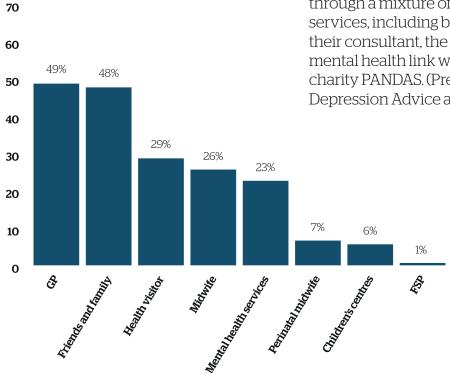
Who did you receive help from?

137 mothers responded to this question. Most said they had received help from their GP, or their friends and family. Almost three in ten received help from a health visitor, and a quarter received help from a midwife.

35 mothers also provided a free-text response to this question. Of these, eight said they did not receive help from anyone:

An additional eight said they received help through counselling, which was provided via a range of channels including children's' centres, in the workplace, and at Addenbrookes Neonatal unit.

The remaining mothers received help through a mixture of individuals and services, including breastfeeding groups, their consultant, the homestart team, mental health link workers, and the charity PANDAS. (Pre And Post Natal Depression Advice and Support).



Which service did you recieve help from? 121 mothers responded to this question. Most mothers (42%) said they received no help.

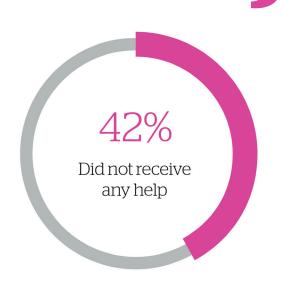
The next most commonly reported answer was medication, with 39% of mothers saying they had been prescribed medicine. 34% received help from a Community Health Team or talking therapies (such as the Wellbeing Service), and 12% received help from the Perinatal Mental Health Service.

Other responses included that 6% had accessed support from the "Crisis team", 2% got help from a "mental health unit" and 2% from a "mother and baby unit".

Were you admitted into a mental health unit?

Of the 140 who responded, three said they had been. Of these, two said they were offered the Mother and Baby Unit (MBU) in Chelmsford (Rainbow Unit). The other mother said she was not offered an MBU.





Service ratings





On average, services were rated:

 $4.4_{\text{out of}}10$

The survey asked respondents to rate the mental health support they received from different individuals and services. Responses were given on a scale of 1 to 10, with 10 being fully met.

The following services were rated:

- GP
- Giving birth in hospital
- Community midwife
- Health Visiting Team
- Mental Health Services

Mothers who experienced depression rated support from the hospital they gave birth in as the lowest. In contrast, mothers who experienced PTSD rated their GP most poorly. Overall, mothers suffering with PTSD reported the lowest ratings.

Community Midwives and Health Visiting Teams were rated most favourably by mothers who had experienced anxiety.

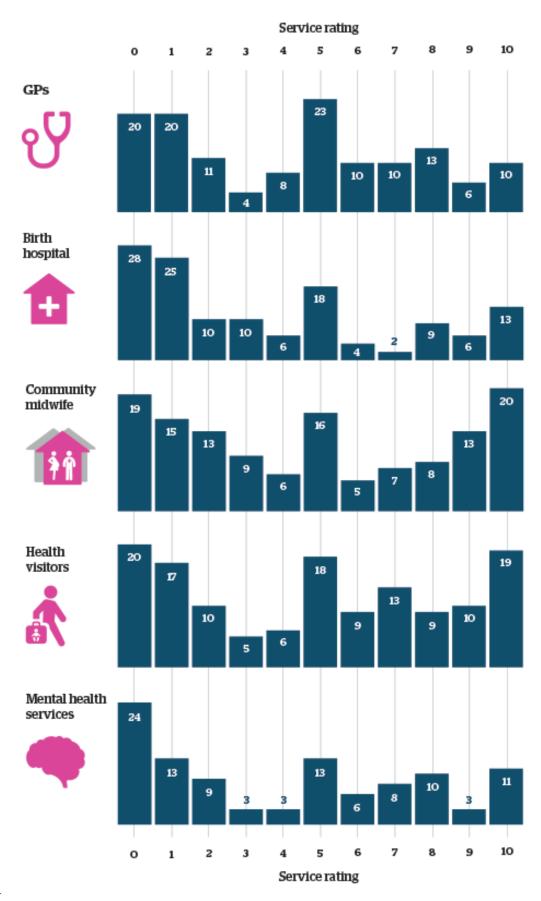
Average rating split by mental illness

An analysis of the four most commonly reported mental illness showed that the average rating for each service varied between illnesses.

*The colours below illustrate the range of scores, from lowest (red) to highest (green).

	Depression	Anxiety	PTSD	Psychosis
GP	4.6	4.5	3.4	4.4
Birth hospital	3.5	3.9	3.7	3.7
Community midwife	4.8	5.2	3.5	4.8
Health visitors	4.9	4.9	3.6	4.9
Mental health services	4.1	4.4	4	4.1

The following graphs show the distribution of responses for each rating. Above each bar chart are the numbers of respondents who selected each rating. Within surveys, people's responses to these types of rating scales tend to fall at either end of the extremes, and in the middle. This trend is reflected in the charts below.



Private treatment

Did you seek private treatment that you paid for yourself?

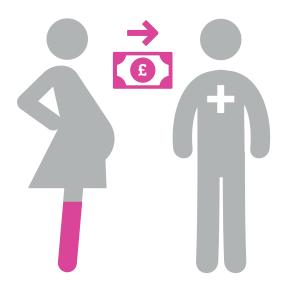
97 mothers responded to this question. Of these, 28% said they had sought private treatment which they had funded themselves.

The percentage seeking private treatment varied between mental illness. Mothers with PTSD were most likely to have sought private treatment.

The breakdown by illness is as follows:

- PTSD (30%)
- Anxiety (29.7%)
- Depression (27.8%)
- Psychosis (27.8%)

of mothers said they had paid for private mental health treatment.

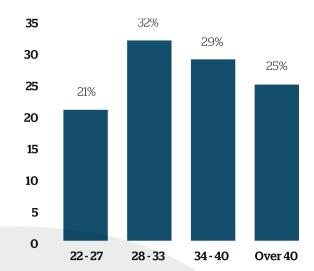




Age groups

The percentage of mothers seeking private treatment also varied between age groups.

Mothers aged between 28 and 33 were most likely to have sought private treatment. One mother said she may seek private treatment to help with difficulties since being discharged from Addenbrooke's.



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"No additional support was available

once we were transferred to Ipswich. I may be seeking additional help soon as I do not feel like I have resolved my anxiety from my son's early birth 18 months on."

"The counsellor at Addenbrooke's offered to refer me after our transfer to Ipswich, but with a baby still in hospital (for another 10 weeks!) I felt it was impractical for me to attend sessions elsewhere as I was spending as much time as I could at the hospital with him."

"Had something been available on the ward - or easily accessible through the SCBU and located on the hospital site - this is absolutely something that I would have used and benefited from"



Types of Private Treatment

29 mothers described the type of private treatment they had accessed.

17 had sought face to face counselling or therapy sessions. These included different types such as CBT, talking therapy, person centred counselling and psychodynamic therapy. The remaining 11 mothers accessed other forms of support, including homeopathy, aromatherapy, hypnosis, mindfulness and nutritional advice.

One had sought private treatment, but couldn't afford it.



"I had 6 one-hour one to one counselling sessions which was exactly what I needed."

"I was seeking private psychotherapy and counselling but it either wasn't available at an affordable rate or **I couldn't afford it.**"



Mental Health Crisis Team

If you received a visit from the Mental Health Crisis Team, what feedback do you have on the service?

Seven mothers responded to this question. Of these, four reported a negative experience:



"Met over 14 members of staff, **no consistency**. Some had no idea what to say. Lack of empathy."

"Understaffed, lack of communication, not able to offer the support asked for: not a man and sent a man etc."



The remaining three mothers reported a mixed experience:



"I found it really difficult to cope with different people from the team coming out to see me; there was no consistency. The team were quite helpful in our time of need, but **support should have been given to my husband as well** as it was such a tough time."

"I had to go to my local hospital. The team were good, but it was difficult traveling." "They would visit more than once a week and were helpful most of the time. **Once the baby was born, they decreased visits dramatically.** I developed psychosis after that."



Would you say that you were able to overcome these mental health problems using the NHS Mental Health Services available in your area?

67 mothers and two partners responded to this question. A sentiment analysis of their responses was conducted to determine whether they were positive, negative or neutral. 70% of comments were negative and 23% were positive. The remaining 7% were neutral or mixed.



"Only thanks to the perinatal mental health nurse I had. My previous experiences haven't been so positive, but this has been my saviour."

"The counselling I received from the children's centre helped the most."

Yes, although I don't feel my case was particularly difficult."

"Sort of. But felt like at one point **I was** being passed around a lot."

"A lot has been due to self-help & the support of my family & friends. We could have done with more support from certain

areas of the MH Services, but can't fault the Perinatal MH Service."

"**Very supportive** and not a long wait to be seen."

"Not overcome, but manage."

"The postnatal depression was **massively helped by medication.** I was referred to an online group counselling programmethis was not effective for me."



'No' responses

25 mothers simply said 'No'. A further 10 said 'No' but also provided more information as detailed below.

Some mothers managed alone:

"No, I had to struggle myself."

"No, I did it myself."

"No, I did it despite **little NHS help.**"

One mother described mental health

services not providing support beyond what her GP had already said:

"No. The mental health services just repeated what I had already been told by my GP."

Another described being prescribed medication:

"No. I was in no fit state to research or investigate options myself, so I was **given medication and muddled on alone.**" Others relied on alternative sources of support:

"No. I went private."

"No. The GP was useful for medication. **Most help came from private counselling.**"

"No. I received counselling from a charity (Petals)."

One mother indicated she deteriorated after seeking NHS support:

"No. I left worse than I went in."

Disclosure of issues

Two mothers did not seek NHS support because they felt unable to disclose their mental health issues.

"I work for local mental health services and so felt unable to acknowledge or ask from help from secondary services."

"**I suffered silently** as thought I should be happy to have healthy twins (had a previous 2nd trimester miscarriage)."

Ongoing illnesses

Three mothers said that they were still suffering from mental health difficulties.

"I still suffer and **don't think I'll** ever be ok".

"I've not yet overcome them & have just rereferred myself for more support."

"I am still taking anti-depressants 10 years after my son was born."

GP Surgery

Three mothers referred to experiences they had when seeking support from their GP. Their journey to getting support started with their GP surgery, but never progressed beyond this.

"I didn't have any support other than from GP"

"The GP and nurse had little interest in any of the post pregnancy issues I've experienced physically, so I haven't raised a mental health issue. I find the team less than interested"

"I wasn't able to get past the doctor's receptionist. It took a lot of courage to make "that call" and I was told to call back in the morning, despite explaining in tears that it was to do with my state of mind."

Health Visiting Team

One mother described issues with her Health Visiting Team:

"The health visitors were some of the nastiest health care professionals I have ever had the misfortune to meet who made me feel I was an inconvenience on several occasion. Review the health visitors and action their appalling attitudes."

Access

Four mothers referred to issues around accessing services. Three had experienced a lack of access to the right service. One anticipated they would encounter a long wait so had chosen to not seek help.

"**No response** from the midwife led counselling when I asked several times."

"I feel strongly that my experience would have been much better had I had access to specialist perinatal mental health support."

"I think mental health services in this area are **severely** **underfunded**. If I pursued support it is likely I would have had a long wait to get help."

"GP was useless and only directed me to a website which you put your name on and you get a well-being meeting months later to go to sit and get offered two other courses miles away on days I couldn't do".

Improvements

How could your experience with the NHS Mental Health Services have been improved? What would you like to see change?

65 mothers and one partner responded to this question. The partner suggested a need for earlier access to one to one support, to prevent issues getting worse.

Positive experiences

Three mothers (4%) commented on having a positive experience of receiving NHS support:

"I had a very good experience."

"The support came from a lovely health visitor, with a brief GP appt and antidepressants."

"Nothing as of yet, the Perinatal Mental health service based in West Suffolk has been **invaluable so** far."

Access

Most mothers (31%) referred to the need for improved access to NHS services. Seven mothers wanted to see shorter waiting times.

Two mothers mentioned the need for support in rural locations.

Reduced waiting times

"More timely access to services such as Suffolk wellbeing. It takes 4 weeks just to speak with them."

"Less of a wait for an NHS counsellor."

"Better call back service, **18 months later I still haven't had mine!**"

"Health visitor referred me but had to wait five weeks for a telephone consultation and there was a three month wait for group CBT. Too long to wait."

"The wait was ages for referral. The live broadcasts were at 6pm a busy time for all families."

"Easier, quicker access to therapy"

I was referred to the postnatal service at West Suffolk Hospital.

No one called or turned up. 33

Rural support

"Offer support within rural areas."

"More regular clinics in rural areas."

Other concerns about availability and access

"[For mental health services] to exist."

"Specific support should be available for at least the first year after birth, rather than being dismissed because 8 months is too late."

"I should have been admitted to an MBU but **there wasn't anything** local."

"Wellbeing service was hard to access and didn't offer suitable support services."

"Being able to access the service I need rather than having to start with stress management and jump through hoops each time."

"More help from health visiting team & easily accessible counselling from NHS."

Trained professionals

18% of mothers would like receive support from professionals who are better trained to support their needs.

14 talked about the need for the health care workforce to be more aware of perinatal mental health issues, and be better equipped to support them - in particular, GPs, surgeries and midwives.

Couite honestly, I have been left in crisis by the entire mess of a service and have literally no options available to me. It is absolutely shocking.

Workforce awareness and upskilling

"More understanding of mental health by all health care practitioners and better treatment by those people."

"A better understanding and recognition of mental health needs from general medical professionals within hospitals and community."

"More staff in the community need to be aware of the perinatal mental health team."

"Mental health workers with an interest in perinatal care should be on the maternity wards, in antenatal clinics and then working alongside health visiting teams and midwives" "Better skills for midwife, health visitor etc."

"Suffolk needs to provide dedicated perinatal mental health specialists rather than relying on universal services who don't have experience in this area."

GPs and surgeries

"For them to recognise postnatal anxiety. I was seen by GPs three times for severe headaches, bearing in mind I had history of these linked to stress and worry - **none of them** made the link."

"GPs focusing more on MH at 6-week check, rather than just asking obligatory question on "baby blues" and dismissing evidence to suggest it's more than a normal hormonal surge that levels with time."

"**More education** within mental health and first port of call such as GPs."

"More understanding doctors' receptionists!"

"Difficult to get initial GP appointment as deemed not urgent."

"The GP I spoke to when I was first pregnant wasn't clued up about depression, medication and

The GP I spoke to when I was first pregnant wasn't clued up about depression, medication and

medication and pregnancy. He told me to come off my medication straight away which caused me significant problems. \$9

pregnancy. He told me to come off my medication straight away which caused me significant problems."

"The GP told me-babies cry, I can't help you."

Midwives

"More monitoring by midwives at antenatal appointments. I repeatedly said I was struggling, and was ignored."

"More perinatal MH midwives as they are key."

Other workforce suggestions

"Have different teams dealing with different severity of mental health problem."

The home visiting team need training to understand that autistic people can get PND

instead of dismissing concerns. The well-being service needs to have specific training in working with autistic mothers rather than saying that their CBT is suitable - it isn't, and it is well known that regular CBT is not appropriate."

General support

12% mentioned a need for better support, and to listen and understand. They want services to have the time to listen to them, and to show they care.

"More support more understanding more caring not treating me like a waste of time."

"Midwife and health visitor

Suffolk needs to provide dedicated perinatal mental health specialists rather than relying on universal services who don't have experience in this area. 99

unhelpful, just needed to fill in the forms, not talk about issues or offer practical help. Services should not be focused on filling in forms but provide time for discussion of issues."

"For people to listen"

"Not being given up on. Not being made to feel like more like a lost cause"

"More mental health support in pregnancy and aftercare."

Early intervention

Eight percent of mothers said earlier intervention and more proactive support is needed. They felt support in early pregnancy would prevent problems becoming worse.

"I would like to have been able to access services sooner in my pregnancy."

"Be aware of at-risk groups and proactively check in them."

"Help available before crisis point

reached. I felt that my baby being ill in hospital and the breastfeeding advice I got in hospital put me in a vulnerable place emotionally."

"Women with existing mental health conditions need support as soon as they are pregnant, especially around managing medication"

"Reach more women around delivery to establish emerging mental health issues."

"I would love to see more support for mums with lower level mental health symptoms to prevent them becoming more unwell rather than getting to the point of needing admission."

12%

expressed a wish for more support that includes time to listen and care.





Seven percent of mothers would like more one-to-one support, often in person (rather than online or on the phone):

"Better access to more one to one support."

"More counselling offered. Not telephone but face to face."

"More one on one sessions as opposed to group sessions."

"Support and one to one counselling rather than just being given a website to click on which doesn't provide what's needed anyway."

"Face to face meeting rather than telephone."

Follow-ups

Five percent of mothers would like to have received a follow-up from mental health services:

"The health visiting team **put my feelings down to the baby blues** and did not follow-up at all."

"More follow up after receiving a course of treatment."

"Make **more time for follow-up** sessions."

"The service I accessed offered selfhelp course to go on but no followup to see whether I had done it."

"The IDT need to be more proactive as I've had to request things such as Med reviews."

Partner support and involvement

Five percent of mothers would like to see more partner involvement:

"Support for spouses/partners."

"Needed relationship counselling as this was the root of the problem but wasn't considered eligible."

"More information for my partner as I couldn't relay the information as my thoughts were distorted."

"More support for partners knowledge, understanding and a listening ear."

Continuity of care

Three percent of mothers would like to see the same staff throughout their treatment:

"Consistency of workers visiting from the Crisis team."

"Continuity in the medical staff I saw during pregnancy would have enabled someone to notice something was wrong. I saw a different midwife at almost every appointment."

Conclusion

The results suggest that availability of services was not meeting the mental health needs of the partners, mothers and mothers-to-be who took part in the survey. 42% of mothers said they were not supported by services, and 28% had sought private treatment. Waiting times appear to be the biggest barrier and deterrent to accessing NHS services.

Mothers called for better awareness and recognition of perinatal mental health across the workforce. In particular, they suggest that GPs must be better equipped to identify problems early on. GPs are likely to be the first person they meet when looking for help, with more mothers saying they received support from their doctor than from their midwife or health visitor. Mothers who experienced PTSD, rated their GP the lowest, indicating a need for improved awareness amongst doctors of the illness and its symptoms.

Respondents also highlighted that early support is key. Whether this is proactively supporting expectant mothers known to have pre-existing issues, or recognising those with emerging, low level symptoms. 93% said they, their friends, or their family had first identified that there was a problem. Only 6% of mothers said their symptoms were first noticed by a midwife or health visitor. Partners also play a key role in identifying problems and should be included in discussions with support staff.

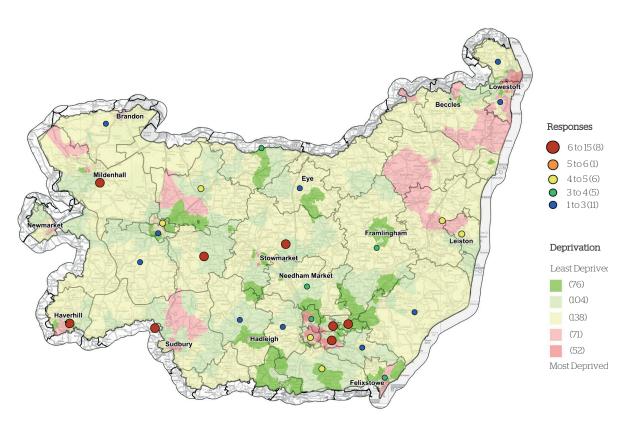
Mothers expressed a preference for oneto-one, face to face counselling, instead of group or online support. Many already indicated that they receive individual counselling privately, suggesting a gap in NHS provision. They also highlighted the need for services to make improvements in how they follow-up with them after they have either raised initial concerns or completed their treatment.

Most mothers first noticed a problem after the birth (68%), with 57% noticing within the first three months post-birth. Mothers with depression or anxiety were more likely to notice a problem within the first month after giving birth. However, mothers with PTSD were more likely to notice a problem slightly later on. Staff providing postnatal support, such as midwives and health visitors, could benefit from the awareness that different illnesses may present at different stages.

Whilst only three male partners completed the survey, their experiences highlight that both men and women are affected by perinatal mental health issues.

Appendix A

$Number\ of\ responses\ by\ location\ and\ level\ of\ deprivation$







This report has been produced for the Suffolk Perinatal Mental Health Steering Group which has oversight of developments to improve access to support for women and partners experiencing mild to moderate perinatal mental ill health in Suffolk.

For information about how Healthwatch Suffolk could support your service development, please contact 01449 703949 or email info@healthwatchsuffolk.co.uk.

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